A Community Based Well Woman’s Programme In A Remote Aboriginal Community

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3rd National Rural Health Conference
Mt Beauty, 3-5 February 1995

Proceedings
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The Well Women's Programme at Yuendumu in the Northern Territory was based on the principles embodied in the World Health Organisation's Declaration of Alma-Ata in 1978 on Primary Health Care.

The aim of this paper is to highlight the critical importance of community participation in the development of a successful women's health programme. This programme promoted community and individual self-reliance and participation in its planning, organisation, operation and control. It was specific to the needs of the people, culturally appropriate, and affordable. It relied on the local skills within the community working as a team in response to the expressed health needs of the community.

Setting

Yuendumu is a ‘dry’, or alcohol free, community with a population of approximately 1,000, mostly Warlpiri, people. It is situated 290 kilometres North West of Alice Springs on Aboriginal Reserve land. Another 500 people live in the surrounding communities. As with other remote communities, Yuendumu has only a basic infrastructure consisting of a school, a church, two local stores, a police station, an art gallery, a Women's Centre, and a health clinic. People still follow many aspects of their traditional culture and ceremonies, dancing, story telling, painting, singing and hunting all continue to influence their day to day lives.

Despite the legislation against alcohol, Yuendumu does have problems with "grog" and in the late 80s local women formed a group to address this problem. They called themselves The Women's Patrol "Girls against Grog". These women would patrol the community nightly and this vigilance helped to reduce the negative effects of alcohol consumption. This initiative reflects the power and community spirit of the women in Yuendumu.

However, Yuendumu suffers from health and social problems similar to those of many other remote Aboriginal communities: poor environmental conditions, high rates of diabetes, heart disease and hypertension, and high rates of childhood illnesses. This provided a daunting task for the health staff which comprise six resident Aboriginal Health Workers, four resident registered nurses and a district medical officer who visits for two to three days each week.
The Focus

In 1993 the Management team of Rural Health formulated a District Plan, and each clinic was instructed to focus on priorities that were achievable. The Director of the Rural District, John Wakerman stated:

"Many of us have experienced one or other strategic or operational plans which, in its comprehensiveness, was all too daunting or because of any lack of involvement, we felt no commitment towards. The intention here is to focus on a small number of priorities as identified by the clients and staff”.

This statement described the feelings of the staff at Yuendumu perfectly. It was evident that women in Yuendumu were exposed to the high rates of STDs and that cervical screening was sporadically and haphazardly performed. We knew that a high proportion of Aboriginal women diagnosed with invasive cervical cancer have never had a Pap smear. The diagnosis of cervical cancer is often at a late stage in Aboriginal women with 43 per cent of the women presenting with invasive cancer, compared to only 15 per cent in non-Aboriginal women. This late presentation contributes to a death rate from cervical cancer among Aboriginal women which in the Northern Territory is six times the national rate. This difference in mortality has been attributed to the scarcity of culturally appropriate resources in remote areas.

With these facts in mind the health staff at Yuendumu were keen to focus their attention on women's health. The death of a twenty-four year old woman from inoperable squamous cell carcinoma of the vagina increased the awareness in the community and prompted a good response to the development of a more comprehensive women's health service. The existing women's networks made the task of implementing a women's health programme feasible.

The Process

In developing this program some of the staff were aware of deficiencies in their knowledge of Aboriginal culture and history and the existence of a number of issues that needed to be addressed with sensitivity and respect.

In an effort to address these inadequacies the non-Aboriginal staff enrolled in an intensive Warlpiri course organised by the Institute of Aboriginal Development in Alice Springs. Participation in women's camps out bush was encouraged by the management of Rural Health. Staff became involved with all the activities that took place at the camps including dancing, singing and hunting with the women. These trips were crucial in providing time to exchange knowledge and develop trust with the women in the community.

The staff discussed how we could develop a programme to improve women's health in Yuendumu and portray the statistics concerning cervical cancer in Aboriginal women in a meaningful way to women in the community.
Our objectives were to:

- make women's screening a priority
- teach women basic anatomy and physiology of the reproductive system
- teach women the benefits of improving their health: increased well being, decreased mortality and morbidity
- teach women about the benefits of family planning; gaining control of their bodies and their fertility
- provide knowledge on the prevention and treatment of STDs
- provide a room in the clinic solely for women

**Strategies**

Every opportunity was taken to talk to the women in the camps, homes and Women's Centre about the value of being healthy. The teaching was carried out by a team comprising the registered nurse and the Aboriginal health worker. The registered nurse supplied the medical knowledge and the Aboriginal Health Worker provided information about local culture and language. Working together, teaching aids were produced that were specific to the local Aboriginal women.

The senior sister (SC) and district medical officer (MG) undertook further training with the Northern Territory Family Planning Association to upgrade their skills. The Aboriginal Health Worker (IN) received training from the Woman's Health Coordinator (AC), and worked with her at Yuendumu and in other Warlpiri communities.

The Woman's Room was established at the back of the clinic and curtains were made by the staff from fabric locally printed at the Women's Centre. A bolt was placed on the inside of the door to ensure privacy.

**Specific Aids**

A poster representing faces of women was placed in the Women's Room. Women chose a face and placed their name on it once they had been screened. This created discussion within the community when other women saw names of relatives on the wall and provided a degree of peer pressure.

Teaching aids were made by the staff using Aboriginal symbols for people; these depicted graphically and in a culturally accessible way the high mortality of Aboriginal women from cervical cancer compared to non-Aboriginal women.

A kit with magnetised pictures of the female reproductive system was donated by the STD clinic in Alice Springs to teach basic anatomy and physiology. This was invaluable in teaching about the menstrual cycle, different methods of contraception and how disease affects women's bodies.
Yuendumu social club donated money for a new examination couch, an angle poise lamp and a "breast with lumps" self examination model. A folder depicting a cervical smear being taken and how to carry out a breast self examination was donated by the Family Planning Association in Darwin.

Documentation

The records in the clinic were examined to produce a data series of the women and their Pap smear history. This included; name, date of birth, community, date and results of Pap smears, and any information of follow up procedures and STDs. Information was recorded on an index card and subsequently entered on computer. Cards were arranged in months with a list of the women due for a Pap smear each month.

Cultural Factors

There were several factors that made the implementation of the programme a challenge. Language was the most obvious hurdle but in many respects this was a valuable obstacle as it reinforced the importance of the Aboriginal staff and maintained the non-Aboriginal staff in a dependant position.

Historically cervical screening had been conducted by an experienced Women's Health sister. However, her association with a rival Aboriginal community made it difficult for her to succeed with women at Yuendumu. There was also a perceived association between cervical screening and promiscuous women or women "belonging" to promiscuous men. Women who came for screening subsequently earn the reputation of women that "had Shame".

Follow up was difficult due to the mobility of Aboriginal people from one community to another. However, local knowledge supplied by the Aboriginal Health Workers meant that often women could be traced and screened via other health clinics. This highlighted the importance of self motivation and self determination. We felt it was vital to provide women with the information to make their own choice concerning cervical screening and that the majority of effort should be put into education and understanding and that this would ultimately result in a more successful programme.

Contact tracing of positive STDs required considerable local knowledge and sensitivity in order to treat all the parties involved without allocation of blame. This made it important to have a good knowledge of the community relationships and dynamics. Polygamy is still practised at Yuendumu and many other Aboriginal communities. It was essential that non-Aboriginal staff were aware that a woman was a co-wife so that all the partners could be screened and treated simultaneously. In these areas the local health workers were an invaluable resource.
Results

Over the first 16 months of the program 416 Pap smears were performed, increasing coverage from 39 to 78 per cent of eligible women. At the start of the program 51 per cent had never had a Pap smear (Figure 1).

Acceptability of the program was excellent with only two per cent (nine women) refusing to have a Pap smear, the majority of whom were older women. Despite the program 54 women (13.4%) still have no record of ever having had a Pap smear (Figure 2).

By the end of the 16 months 77 per cent of the smears were carried out by the nursing staff resident in the community, the remaining few by the visiting district medical officer. Quality control was excellent, with only six per cent showing no endocervical cells. This is well within the guidelines set by the Family Planning Association. Fifty-five per cent of the smears were reported as normal and only two per cent showed evidence of atypia (Table 1).

With time, knowledge and empowerment, women came to realise that women’s health was for all women not just for women who were promiscuous. Gradually women began accepting screening and would return voluntarily to the clinic for results. These were explained with pictorial representations of cells and dysplasia. If necessary, treatment was discussed with the woman and her family. Women were given a recall card indicating the date of their next Pap smear and told when this was due. Later women voluntarily came to the clinic requesting a Pap smear and contraception was more openly discussed and requested.

Conclusion

In developing this programme we have followed the principles embodied in the principles stated in declaration six of Alma-Ata namely;

"Primary health care is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally acceptable to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self reliance and self determination. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process."

During the 16 months of this program a special relationship grew between the staff at Yuendumu and with the women of the community. Despite coming from different cultures, backgrounds and experience, because of a mutual respect for each other’s differences and a common interest, we learnt to work in harmony. The success of our programme was due to the fact that the Aboriginal Health Workers and women in the community felt some ownership of the programme. It was affordable thanks to community and regional financial support. The involvement of the local staff and the women in the community early in the development of the programme meant that the programme was culturally appropriate and acceptable.
Acknowledgments

This programme would never have started without the energy and interest of the women in Yuendumu. The acceptance and support from the Community Council allowed for its development and survival. We are grateful for the moral and financial support provided by the Northern Territory Women's Health Program and the management of Rural Health. Thank you.

Figure 1: Proportion of eligible women screened for cervical cancer, 1987-1993

*Data compiled from the review of medical records in Yuendumu.
Table 1: Results of cervical screening of Aboriginal women in Yuendumu, Yuelumu and Nyrripi, Northern Territory 1992-1993

<table>
<thead>
<tr>
<th>Pap smear result</th>
<th>Number of women</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No endocervical cells</td>
<td>27</td>
<td>8.5</td>
</tr>
<tr>
<td>No abnormality</td>
<td>176</td>
<td>55.7</td>
</tr>
<tr>
<td>Inflammation</td>
<td>104</td>
<td>32.9</td>
</tr>
<tr>
<td>Mild atypia</td>
<td>5</td>
<td>1.6</td>
</tr>
<tr>
<td>CIN I</td>
<td>2</td>
<td>0.6</td>
</tr>
<tr>
<td>CIN II</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>CIN III</td>
<td>1</td>
<td>0.3</td>
</tr>
<tr>
<td>Squamous cell carcinoma</td>
<td>1</td>
<td>0.3</td>
</tr>
<tr>
<td>Total number of women</td>
<td>316</td>
<td>100</td>
</tr>
</tbody>
</table>

Prevalence of cervical intraepithelial neoplasia (CIN): 0.9% (95% confidence interval 0.4%-1.4%)